



General

Guideline Title

Transitioning HIV-infected adolescents into adult care.

Bibliographic Source(s)

New York State Department of Health. Transitioning HIV-infected adolescents into adult care. New York (NY): New York State Department of Health; 2011 Jun. 33 p. [29 references]

Guideline Status

This is the current release of the guideline.

Recommendations

Major Recommendations

The quality of evidence (I-III) and strength of recommendation (A-C) are defined at the end of the "Major Recommendations" field.

Challenges and Barriers to a Successful Transition

See Appendix A, "Challenges to Successful Transitioning," in the original guideline document for information on common challenges of transition, human immunodeficiency virus (HIV)-specific challenges, and challenges specific to both perinatally and behaviorally infected adolescents.

Preparing for Transition in the Pediatric/Adolescent Care Setting

The pediatric/adolescent care provider should:

- Develop a transition plan several years prior to transition and update it at regular intervals. (AIII)
- Ensure that HIV-infected youth understand their chronic illness and its management, and provide them with skills to negotiate care in an adult clinic setting (see the table below). (AIII)
- Assess patients, in an individualized manner, for development of sufficient skills and understanding for successful transition. (AIII)
- Address the individual barriers for each patient that may be preventing him/her from acquiring skills, such as developmental delays, anxiety, post-traumatic stress disorder, transient living conditions. (AIII)
- Prepare and discuss a current medical history with the patient so that he/she is aware of previous hospitalizations or allergies that may have occurred during infancy or childhood. (AIII)

Developing a Transition Plan

The pediatric or adolescent care provider should collaborate with the patient and family to develop a transition plan that spans several years with

concrete goals and a timeline. Whenever possible, a written transition plan should be developed at least 3 years before the transition is planned and should be updated at least annually. (AIII)

For adolescents who do not yet know their HIV status, disclosure should be a primary goal of the transition plan. (AIII)

As part of the transition plan, arrangements should be made for transitioning patients to meet their new providers well in advance of their final appointment with their pediatric or adolescent primary care provider. (AIII)

See Table 2 in the original guideline document for clinical considerations in perinatally infected versus behaviorally infected adolescents.

Education and Skills Training for Adolescent Patients

The pediatric or adolescent care provider should offer training and practice in the specific skills that the patient will need in the adult clinic setting and should evaluate the patient's progress toward these goals (see the table below). (AIII)

The pediatric or adolescent care provider should ensure that HIV-infected youth understand their chronic illness and its management. (AIII)

Table. Skills to Assist Adolescents in Achieving Successful Transition to an Adult Clinic

Ideally, the adolescent should be able to do the following before transitioning:

- Know when to seek medical care for symptoms or emergencies
- Identify symptoms and describe them
- Make, cancel, and reschedule appointments
- Arrive to appointments on time
- Call ahead of time for urgent visits
- Request prescription refills correctly and allow enough time for refills to be processed before medications run out
- Negotiate multiple providers and subspecialty visits
- Understand the importance of health insurance, how to select an appropriate healthcare plan, and how to obtain it and renew it
- Understand entitlements and know how to access them
- Establish a good working relationship with a case manager at the pediatric/adolescent site, which will enable the adolescent to work effectively with the case manager at the adult site

Identifying the Adult Care Provider

The referring provider should identify an adult care provider or multidisciplinary team that:

- Is experienced with caring for transitioning HIV-infected adolescents and young adults. (AIII)
- Is willing to engage in direct communication with the referring provider about the patient. (AIII)
- Accepts the patient's health insurance. (AIII)

The Importance of Using a Multidisciplinary Approach

HIV care should be provided in settings where patients can receive all services in one location from a multidisciplinary team. If a multidisciplinary team is not available, mental health and psychosocial support services should be available onsite or in an easily accessible location. The primary care team should be responsible for maintaining an ongoing plan for coordination of care among all service providers. (AIII)

In areas where comprehensive HIV services are not available, the patient should be referred to a primary care provider with experience in providing HIV care in addition to a provider experienced with antiretroviral therapy (ART) management. The primary care provider should help the transitioning patient navigate the adult subspecialty clinic model. (AIII)

If gynecologic services are not available as part of a comprehensive care model in the adult HIV care program, the primary care provider should refer HIV-infected adolescents/young women to a gynecologist with expertise in counseling adolescents regarding reproductive health and perinatal transmission. (AIII)

The primary care provider and members of the multidisciplinary team also should be able to provide ongoing HIV transmission and risk-reduction counseling to adolescents. (AI)

Key Point:

When care is complex or fragmented, assignment of a specific staff person, such as a nurse, case manager, or social worker, to a coordinating role is important to ensure that a comprehensive and effective management plan is implemented that includes optimal support and follow-up.

Preparing for Transitioning Patients in the Adult Care Setting

The adult care provider should:

- Become knowledgeable regarding the challenges of transition for older adolescents and young adults to an adult care setting. (AIII)
- Prior to transition, learn from the referring provider the particular challenges and goals for the patient; consider how to continue building the adolescent's skills. (AIII)
- Meet the patient, with or without family members, before the change in care. (AIII)
- Assign one clinic staff member as point person and have his/her contact information available, including hours when contact is possible (see "Use of Transition Agent or Patient Advocate" section below). (AIII)
- Have an orientation plan in place to acquaint the newly transitioned patient to the new clinic environment. (AIII)

Implementing the Transition Plan

The referring clinician or provider team should arrange the transitioning of all current and anticipated services, including medical, mental health, and substance use treatment if needed. Individualized psychosocial needs, such as housing, employment, education, insurance, home-based services, or transportation, should also be addressed at this time. (AIII)

When to Transition

The transition plan should be implemented when the patient:

- Demonstrates understanding of his/her disease and its management (AIII)
- Demonstrates the ability to make and keep appointments (AIII)
- Knows when to seek medical care for symptoms or emergencies (AIII)

Whenever possible, transition should be implemented when the patient's disease is clinically stable. (BIII)

Communication Between the Adolescent Care Provider and the Adult Care Provider

The referring clinician should:

- Compose a medical summary that highlights key issues for the individual patient and includes the patient's medical, psychological, and social history. (AIII)
- Schedule a case conference prior to transition. (AIII)

Use of Transition Agent or Patient Advocate

The adolescent care provider should designate one member of the healthcare team to oversee transition planning and implementation at both the old and new provider locations. (AIII)

The adult care provider should also designate a point person who will oversee the transition and who the patient can contact with any questions or concerns. (AIII)

Challenges for Pregnant Adolescents during Transition

Adolescent care providers should have referral agreements with obstetrical services that can provide prenatal care to HIV-infected females during transition and that offer prenatal support services. (AIII)

Pediatric and/or adolescent care providers should be able to provide individualized support and advocacy for pregnant teens who are unprepared for transition to obstetrical services. (AIII)

Adolescent care providers should consider remaining the primary care provider for the adolescent during pregnancy. (AIII)

For recommendations regarding care for HIV infected pregnant adolescents.

Role of the Adult Care Provider during the Transition Period

The adult care provider or multidisciplinary team should:

- Assign an appropriate clinic staff person to be the primary contact person for newly transitioned adolescents and young adult patients. (AIII)
- Have a plan for identifying and managing problems that could interfere with continuity of care. (BIII)

Evaluation after Transition Has Occurred

Post-Transition Assessment by the Adult Care Provider or Team

The adult care provider or team should devise a plan to achieve the following on an ongoing basis:

- Assessment of whether an individual patient is adequately caring for his/her own health. (AIII)
- Assessment of barriers that the patient is facing, what support is needed, and who will provide this support. (AIII)
- Skills training and support, either through the multidisciplinary team in the clinic or by liaison with a mental health or psychosocial support provider. (AIII)

Follow-up from Adolescent or Pediatric Care Provider

If adolescents withdraw from care in the adult clinic and return to their previous pediatric/adolescent clinic, the adolescent care provider should be prepared to help the patient identify services that can provide increased support and should encourage re-engagement in adult medical care. (AIII)

Definitions:

Quality of Evidence for Recommendation

- I. One or more randomized trials with clinical outcomes and/or validated laboratory endpoints
- II. One or more well-designed, non-randomized trials or observational cohort studies with long-term clinical outcomes
- III. Expert opinion

Strength of Recommendation

- A. Strong recommendation for the statement
- B. Moderate recommendation for the statement
- C. Optional recommendation

Clinical Algorithm(s)

None provided

Scope

Disease/Condition(s)

Human immunodeficiency virus (HIV) infection

Guideline Category

Counseling

Management

Clinical Specialty

Allergy and Immunology

Family Practice

Infectious Diseases

Internal Medicine

Obstetrics and Gynecology

Pediatrics

Psychiatry

Psychology

Intended Users

Advanced Practice Nurses

Health Care Providers

Nurses

Physician Assistants

Physicians

Psychologists/Non-physician Behavioral Health Clinicians

Public Health Departments

Social Workers

Guideline Objective(s)

To assist providers with the transition process to ensure that human immunodeficiency virus (HIV)-infected young adults are successfully and seamlessly integrated into an adult care setting

Target Population

Human immunodeficiency virus (HIV)-infected adolescents and young adults transitioning into adult care

Interventions and Practices Considered

1. Developing a transition plan several years prior to transition, in collaboration with the patient and family
2. Assessing patients' skills for transition and barriers to acquiring skills
3. Offering training and practice in the specific skills that the adolescent patient will need in the adult clinic setting
4. Ensuring that the patient understands his or her illness and its management
5. Identifying the adult care provider or multidisciplinary team
6. Developing and following an orientation plan in the adult clinic
7. Addressing comprehensive care needs as part of transition, including medical, psychosocial, and financial aspects of transitioning
8. Addressing the needs of the pregnant adolescent patient during transition
9. Post-transition assessment by the adult care provider or team
10. Continued communication between pediatric/adolescent and adult providers after transition

Major Outcomes Considered

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

MEDLINE was searched up to January 2011 with use of appropriate key words. Results were limited to publication years 2000-2011. Due to lack of randomized controlled trials on this subject, evidence is limited to qualitative studies, reviews, and case reports. Studies of transition programs in other chronic diseases were reviewed due to lack of studies of transition in HIV-infected adolescents. Additional information was gleaned from online resources from credible medical websites.

Number of Source Documents

Not stated

Methods Used to Assess the Quality and Strength of the Evidence

Expert Consensus (Committee)

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Quality of Evidence for Recommendation

- I. One or more randomized trials with clinical outcomes and/or validated laboratory endpoints
- II. One or more well-designed, non-randomized trials or observational cohort studies with long-term clinical outcomes
- III. Expert opinion

Methods Used to Analyze the Evidence

Review

Description of the Methods Used to Analyze the Evidence

Not stated

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

AIDS Institute clinical guidelines are developed by distinguished committees of clinicians and others with extensive experience providing care to people with human immunodeficiency virus (HIV) infection. Committees* meet regularly to assess current recommendations and to write and update guidelines in accordance with newly emerging clinical and research developments.

The Committees* rely on evidence to the extent possible in formulating recommendations. When data from randomized clinical trials are not available, Committees rely on developing guidelines based on consensus, balancing the use of new information with sound clinical judgment that results in recommendations that are in the best interest of patients.

*Current committees include:

- Medical Care Criteria Committee
- Committee for the Care of Children and Adolescents with HIV Infection
- Dental Standards of Care Committee
- Mental Health Guidelines Committee
- Committee for the Care of Women with HIV Infection
- Committee for the Care of Substance Users with HIV Infection
- Physicians' Prevention Advisory Committee
- Pharmacy Advisory Committee

Rating Scheme for the Strength of the Recommendations

Strength of Recommendation

- A. Strong recommendation for the statement
- B. Moderate recommendation for the statement
- C. Optional recommendation

Cost Analysis

A formal cost analysis was not performed and published cost analyses were not reviewed.

Method of Guideline Validation

External Peer Review

Description of Method of Guideline Validation

All guidelines developed by the Committee are externally peer reviewed by at least two experts in that particular area of patient care, which ensures depth and quality of the guidelines.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of supporting evidence is identified and graded for each recommendation (see the "Major Recommendations" field).

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

Successful transitioning of human immunodeficiency virus (HIV)-infected adolescents into adult care

Potential Harms

Appendix A in the original guideline document, "Challenges to Successful Transitioning," lists common challenges of transition, human immunodeficiency virus (HIV)-specific challenges, and challenges specific to both perinatally and behaviorally infected adolescents.

Qualifying Statements

Qualifying Statements

When formulating guidelines for a disease as complex and fluid as human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), it is impossible to anticipate every scenario. It is expected that in specific situations, there will be valid exceptions to the approaches offered in these guidelines and sound reason to deviate from the recommendations provided within.

Implementation of the Guideline

Description of Implementation Strategy

The AIDS Institute's Office of the Medical Director directly oversees the development, publication, dissemination and implementation of clinical practice guidelines, in collaboration with The Johns Hopkins University, Division of Infectious Diseases. These guidelines address the medical management of adults, adolescents and children with human immunodeficiency virus (HIV) infection; primary and secondary prevention in medical settings; and include informational brochures for care providers and the public.

Guidelines Dissemination

Guidelines are disseminated to clinicians, support service providers, and consumers through mass mailings and numerous AIDS Institute-sponsored educational programs. Distribution methods include the HIV Clinical Resource website, the Clinical Education Initiative (CEI), the AIDS Educational Training Centers (AETC), and the HIV/AIDS Materials Initiative. Printed copies of clinical guidelines are available for order from the New York State Department of Health (NYSDOH) Distribution Center.

Guidelines Implementation

The HIV Clinical Guidelines Program works with other programs in the AIDS Institute to promote adoption of guidelines. Clinicians, for example, are targeted through the CEI and the AETC. The CEI provides tailored educational programming on site for health care providers on important topics in HIV care, including those addressed by the HIV Clinical Guidelines Program. The AETC provides conferences, grand rounds and other programs that cover topics contained in AIDS Institute guidelines.

Support service providers are targeted through the HIV Education and Training initiative which provides training on important HIV topics to non-physician health and human services providers. Education is carried out across the State as well as through video conferencing and audio conferencing.

The HIV Clinical Guidelines Program also works in a coordinated manner with the HIV Quality of Care Program to promote implementation of HIV guidelines in New York State. By developing quality indicators based on the guidelines, the AIDS Institute has created a mechanism for measurement of performance that allows providers and consumers to know to what extent specific guidelines have been implemented.

Finally, best practices booklets are developed through the HIV Clinical Guidelines Program. These contain practical solutions to common problems related to access, delivery or coordination of care, in an effort to ensure that HIV guidelines are implemented and that patients receive the highest level of HIV care possible.

Implementation Tools

Chart Documentation/Checklists/Forms

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

New York State Department of Health. Transitioning HIV-infected adolescents into adult care. New York (NY): New York State Department of Health; 2011 Jun. 33 p. [29 references]

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2011 Jun

Guideline Developer(s)

New York State Department of Health - State/Local Government Agency [U.S.]

Source(s) of Funding

New York State Department of Health

Guideline Committee

Adolescents with HIV Infection Subcommittee

HIV Transitional Care Work Group

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Financial Disclosures/Conflicts of Interest

Not stated

Guideline Status

This is the current release of the guideline.

Guideline Availability

Electronic copies: Available from the [New York State Department of Health AIDS Institute Web site](#) .

Availability of Companion Documents

Various forms and checklists, including a transition tool, an adolescent individualized transition plan, a transition healthcare assessment, and a skills checklist (Project STAY) are included in the appendices of the [original guideline document](#) .

Patient Resources

None available

NGC Status

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